

# 81. Provider - Survivor Communication: Identifying and addressing unmet needs



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## BACKGROUND

An estimated 14.5 million cancer survivors live in the United States<sup>1</sup>. In Georgia, there are currently 355,870 survivors<sup>1</sup>. It is predicted that the number of survivors 5 years post diagnosis will increase to 37% within the decade<sup>2</sup>

Georgia has a long standing history of collaboration to assess and enhance the quality of survivorship care in the state with leaders from the Georgia Department of Public Health (DPH), Georgia Center for Oncology Research and Education (Georgia CORE), Andrew Young School of Policy Studies at Georgia State University, Regional Cancer Coalitions of Georgia, American Cancer Society, Georgia Society of Clinical Oncology (GASCO), and the Emory University Rollins School of Public Health, among others .

Representatives from these organizations and other organizations serve as members of Georgia's Cancer Control Consortium (GC3), who leads the Cancer Control Plan.

One of the eight priorities of the plan is focused on Survivorship. In 2013, the GC3 Survivorship Working Group (SWG) began work on a statewide survivors' needs assessment to understand the physical, psychosocial, practical and spiritual needs of adult cancer survivors. While needs of cancer survivors have been assessed, there is less knowledge about unmet needs<sup>3</sup>.



## OBJECTIVES

1. To understand the physical, psychological, practical, and spiritual needs of adult cancer survivors in Georgia.
2. To identify the existing support services and resources; to understand access and receipt of the services that exist in Georgia.
3. To determine if cancer survivors' needs are being met in Georgia.

## METHODS

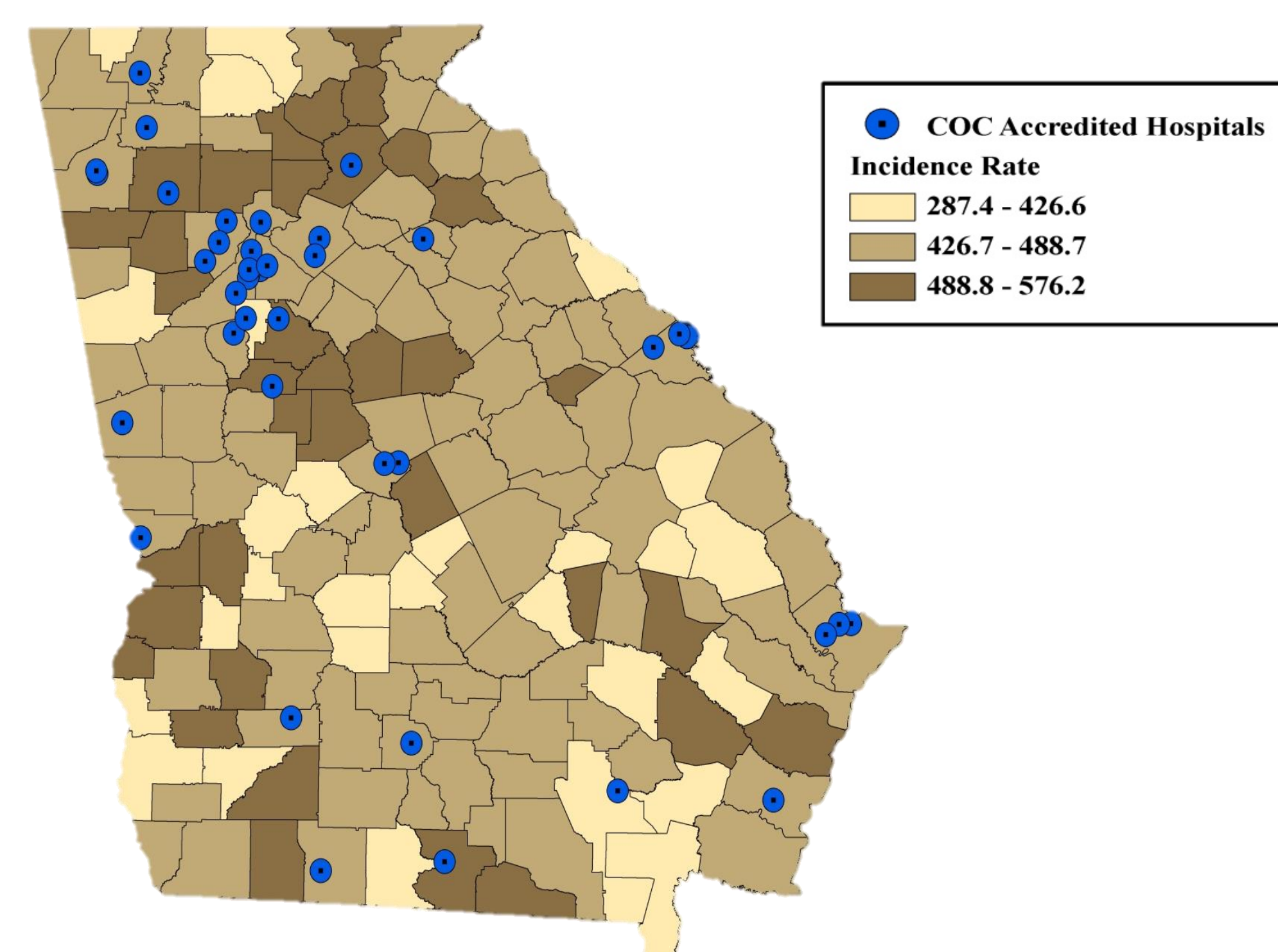
The GC3 SWG and the Rollins School of Public Health developed a cross-sectional survey using National Comprehensive Cancer Network (NCCN) and Commission on Cancer (CoC) guidelines.

Key learnings from the pilot were used to develop the final instrument, which was approved by the Institutional Review Board (IRB) of Emory University in 2014.

In 2014, a convenience sample of Georgia cancer survivors completed a paper or online survey about the presence of and distress associated with unmet physical, emotional, spiritual, and practical needs, and receipts of assistance in those areas. There were also asked about receipt of cancer Treatment Summaries (TS) and Survivorship Care Plans.

### Survey Methodology

- 76 items
- Recruitment & Dissemination
  - Adult cancer survivors who had completed treatment and live in the state of Georgia.
  - Distributed through survivorship programs of the CoC hospitals (n = 40), 16 Survivorship-focused non-profit organizations, and 5 Regional Cancer Coalitions via email, social media and mail.
- 740 responses received September - December 2014.
- Respondents resided in 48% of Georgia Counties (n=159)
- Treated at 72% of CoC hospitals (n=40)

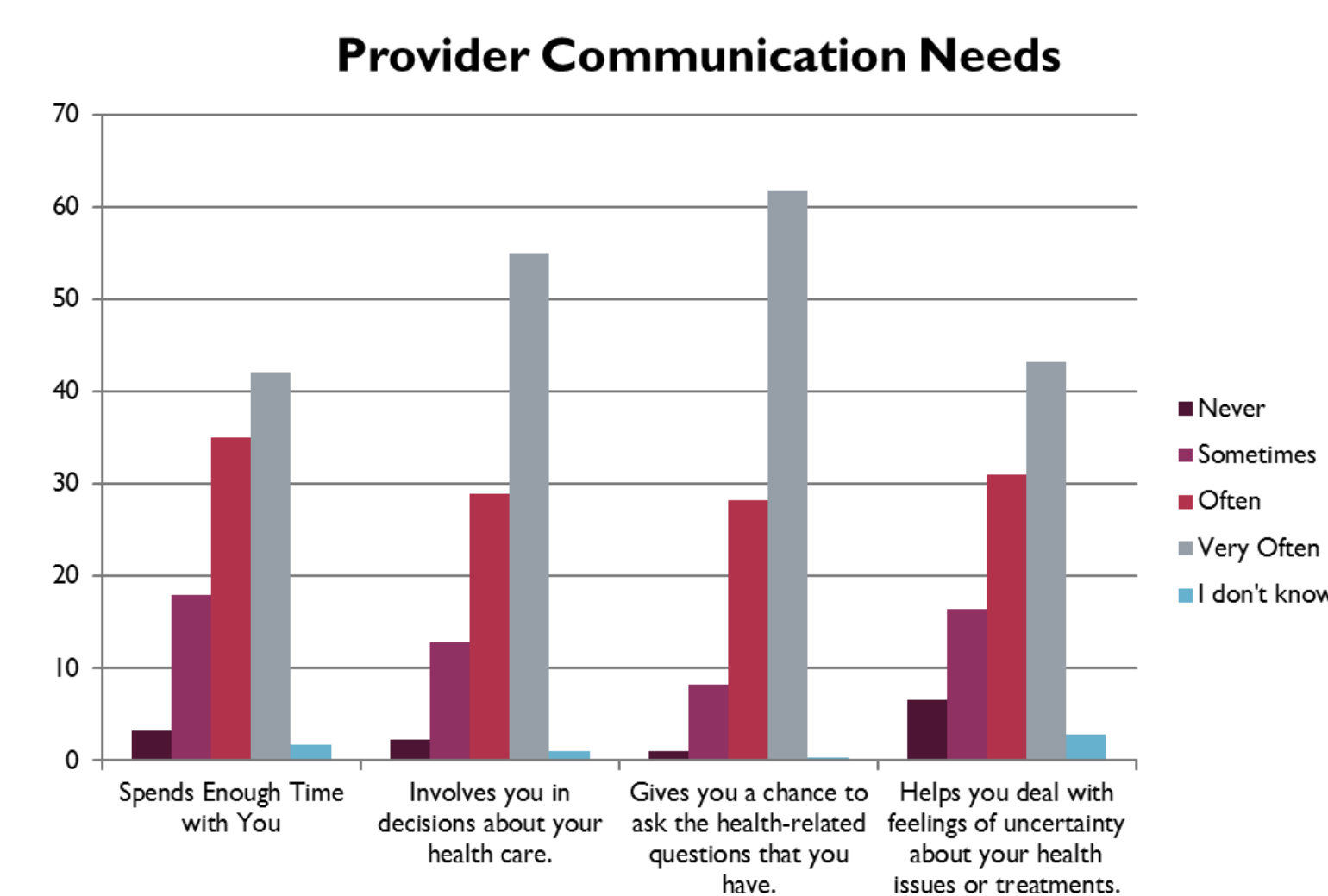


## RESULTS

Respondents were primarily female (78%) married (65%), college-educated (55%) and insured (97%). 83% were White, 16% were African American and 3% were Hispanic. 36% of respondents were within 1 year of treatment; 45% were 1 - 5 years post treatment.

Survivors reported positive experiences with Provider Communication. Responses of 'often' or 'very often' were:

- 90.6% provider gave them a chance to ask questions .
- 84.7% provider involved them in healthcare decisions .
- 78.5% provider spent enough time with them.
- 75.7% provider helped with feelings of uncertainty about health issues or treatment.



Physical and emotional needs were not as effectively met as spiritual or practical needs.

- Over 25% of survivors report physical health needs:
  - Sleep (46.4%); pain (44%); tiredness (42.7%); neuropathy/tingling (31.2%).
- A higher proportion of survivors reported moderate to extreme levels of emotional distress with:
  - depression (32.7%), anxiety (32.1%), stress (30.2%), fear of recurrence (28.2%) and defining a "new normal" (25.9%).

Information, Support and Resources

- 81% of survivors found information and assistance online (56%), in print materials (41%) and from providers/cancer centers (41%).
- 37% received a survivorship care plan (SCP); 98% reported the SCP was helpful.
- 48% received a Treatment Summary (TS); 98% reported the TS as helpful.

## CONCLUSIONS

Results demonstrate the need for providers in Georgia to be educated about and responsive to survivors' unmet needs and levels of distress.

Survivors report positive communication with providers but lower levels of having physical and emotional needs addressed. Survivors actively seek resources and benefit from SCPs.

Providers can contribute to addressing needs and reducing distress by maintaining strong communication, guiding survivors to evidence-based resources and implementing SCPs.

One important resource launched in 2014, Georgia's [Cancer Survivorship Connection](#) (CSC) is the first statewide comprehensive online portal that provides evidence-based survivorship information and resources for Georgia survivors, caregivers and healthcare professionals.

The site will be enhanced to insure survivorship resources are available and highlighted to address the unmet needs.



## REFERENCES

1. American Cancer Society. Cancer Treatment & Survivorship Facts & Figures 2014-2015. American Cancer Society. 2015.
2. de Moor JS, Mariotto AB, Parry C, Alfano CM, Padgett L, Kent EE., et al. Cancer survivors in the United States: prevalence across the survivorship trajectory and implications for care. Cancer Epidemiol Biomarkers Prev. 2013;22(4):561-570.
3. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. Support Care Cancer. 2009;17(8):1117-28.

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